



DEPARTMENT OF HEALTH AND HUMAN SERVICES

Health Resources and Services Administration

Advisory Committee on Heritable Disorders in Newborns and Children

AGENCY: Health Resources and Services Administration (HRSA), Department of Health and Human Services (HHS).

ACTION: Notice of meeting.

SUMMARY: In accordance with the Federal Advisory Committee Act, this notice announces that the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) will hold a public meeting.

DATES: Thursday, August 2, 2018, from 9:30 a.m. to 5:00 p.m. Eastern Time (ET).

ADDRESSES: This meeting is a webinar only and requires advanced registration. Please register online at <http://www.achdncmeetings.org/> by 12:00 p.m. ET on July 30, 2018.

FOR FURTHER INFORMATION CONTACT: Ann Ferrero, Maternal and Child Health Bureau (MCHB), HRSA, in one of three ways: 1) send a request to the following address: Ann Ferrero, MCHB, HRSA 5600 Fishers Lane, Room 18N100C, Rockville, MD 20857; 2) call 301-443-3999; or 3) send an email to AFerrero@hrsa.gov.

SUPPLEMENTARY INFORMATION:

Background: The ACHDNC provides advice and recommendations to the Secretary of HHS on the development of newborn screening activities, technologies, policies, guidelines, and programs for effectively reducing morbidity and mortality in newborns and children having, or at risk for, heritable disorders. In addition, ACHDNC's recommendations regarding inclusion of additional conditions for screening, following adoption by the Secretary, are evidence-informed

preventive health services provided for in the comprehensive guidelines supported by HRSA through the Recommended Uniform Screening Panel (RUSP) pursuant to section 2713 of the Public Health Service Act (42 U.S.C. 300gg-13). Under this provision, non-grandfathered group health plans and health insurance issuers offering group or individual health insurance are required to provide insurance coverage without cost-sharing (a co-payment, co-insurance, or deductible) for preventive services for plan years (i.e., policy years) beginning on or after the date that is one year from the Secretary's adoption of the condition for screening.

Agenda: During the August 2, 2018, meeting, the ACHDNC will discuss issues related to long-term follow-up, timeliness, education and training, the evidence-based review process, and risk assessment in newborn screening. Information about the ACHDNC, a roster of members, and the meeting agenda, as well as past meeting summaries, is located on the ACHDNC website: <https://www.hrsa.gov/advisory-committees/heritable-disorders/index.html>.

Public Participation: Members of the public will have the opportunity to provide comments, which are part of the official Committee record. To submit written comments or request time for an oral comment at the meeting, please register online by 12:00 p.m. ET on July 27, 2018, at <http://www.achdncmeetings.org>. Oral comments will be honored in the order they are requested and may be limited as time allows. Individuals associated with groups or who plan to provide comments on similar topics may be asked to combine their comments and present them through a single representative. No audiovisual presentations are permitted. Written comments should identify the individual's name, address, email, telephone number, professional or organization affiliation, background or area of expertise (i.e., parent, family member, researcher, clinician, public health, etc.) and the topic/subject matter.

Amy P. McNulty,

Acting Director,

Division of the Executive Secretariat.

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